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Abstract: Follow-up care is important for childhood cancer survivors to facilitate early detection and treatment of late effects. We aimed to describe preferences for different organisational aspects and models of follow-up care among Swiss childhood cancer survivors, and characteristics associated with preferences for different models. We contacted 720 survivors aged 18+ years, diagnosed with cancer after 1990 (age 0-16 years), registered in the Swiss Childhood Cancer Registry (SCCR), and Swiss resident, who previously participated in a baseline survey. They received questionnaires to assess attendance and preferences for follow-up (rated on 4-point scales, 0-3). Clinical information was available from the SCCR. Survivors (n = 314: response rate 43.6%; 47.8% still attended follow-up) rated clinical reasons for follow-up higher than supportive reasons ($p < .001$). They rated checking for cancer recurrence (mean = 2.78, SD = 0.53) and knowing about risks for my children most important (mean = 2.22, SD = 0.83). They preferred to attend a children's hospital (mean = 1.94, SD = 1.11), adult hospital (mean = 1.86, SD = 0.98) or general practitioner (mean = 1.86, SD = 1.01) rather than a central specialised late effects clinic (mean = 1.25, SD = 1.06, $p < .001$), and be seen by paediatric (mean = 2.24, SD = 0.72) or medical oncologist (mean = 2.17, SD = 0.69). Survivors preferred decentralised clinic-based follow-up, rather than one central specialised late effects clinic. Survivors' preferences should be considered to ensure future attendance.

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Preferences for long-term follow-up care in childhood cancer survivors

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ABSTRACT

Follow-up care is important for childhood cancer survivors to facilitate early detection and treatment of late-effects. We aimed to describe preferences for different organisational aspects and models of follow-up care among Swiss childhood cancer survivors, and characteristics associated with preferences for different models. We contacted 720 survivors aged 18+ years, diagnosed with cancer after 1990 (age 0-16 years), registered in the Swiss Childhood Cancer Registry (SCCR), and Swiss resident, who previously participated in a baseline survey. They received questionnaires to assess attendance and preferences for follow-up (rated on 4 point scales, 0-3). Clinical information was available from the SCCR. Survivors (n=314: response rate 43.6%; 47.8% still attended follow-up) rated clinical reasons for follow-up higher than supportive reasons ($p<0.001$). They rated *checking for cancer recurrence* (mean=2.78, SD=0.53) and knowing about *risks for my children* most important (mean=2.22, SD=0.83). They preferred to attend a children's hospital (mean=1.94, SD=1.11), adult hospital (mean=1.86, SD=0.98) or general practitioner (mean=1.86, SD=1.01) rather than a central specialised late effects clinic (mean=1.25, SD=1.06, $p<0.001$), and be seen by paediatric (mean=2.24, SD=0.72) or medical oncologist (mean=2.17, SD=0.69). Survivors preferred decentralised clinic-based follow-up, rather than one central specialised late effects clinic. Survivors' preferences should be considered to ensure future attendance.

Keywords: oncology, survivors, aftercare, patient preference, organization

INTRODUCTION

Follow-up care is vital for many childhood cancer survivors due to the high risk of late effects (Geenen *et al.*, 2007, Hudson *et al.*, 2013, Oeffinger *et al.*, 2006). Follow-up offers potential for early detection and treatment of late effects and an opportunity to offer age-appropriate information about disease, treatment and a healthy lifestyle, practical advice about insurance, education or work, and psychosocial support (von der Weid and Wagner, 2003, Gianinazzi *et al.*, 2014, Vetsch *et al.*, 2015). Published guidelines describe risk-based follow-up for childhood cancer survivors (Scottish Intercollegiate Guidelines Network (SIGN), 2004, Stichting Kinderoncologie Nederland (SKION), 2010, Children's Oncology Group, 2013), and evidence-based, risk-adapted examinations. Despite the potential advantages of follow-up, attendance is often low (Michel *et al.*, 2011b, Rebholz *et al.*, 2011, Essig *et al.*, 2012).

Previous studies highlighted the importance of assessing survivors' views and preferences about follow-up care (Aslett *et al.*, 2007, Earle *et al.*, 2005, Michel *et al.*, 2009) to ensure it is relevant to survivors and consequently associated with good attendance. However, little is known about survivors' views of follow-up. They appear more interested in medical aspects of follow-up care such as checking for relapse, late effects and general health status, compared with gaining information about wider issues such as effects of cancer on employment or education, or health behaviour (Michel *et al.*, 2009, Eiser *et al.*, 1996). Organisational issues such as waiting time or length of consultation influenced satisfaction with care (Absolom *et al.*, 2006).

Other work has addressed preferences for different models of follow-up care (e.g. continuation of care with the paediatric oncologist, transfer to adult clinic or general practitioner (GP), or follow-up by telephone/questionnaire). Most survivors were satisfied with the care they received (Eiser *et al.*, 1996, Michel *et al.*, 2011a), and wished to continue this model of follow-up (paediatric or adult clinic) (Absolom *et al.*, 2006, Michel *et al.*, 2009). Two qualitative studies concluded that GP follow-up was convenient but survivors were not confident about GPs knowledge about survivorship-specific care (Zebrack *et al.*, 2004, Earle *et al.*, 2005). However, most studies only included survivors attending follow-up appointments and therefore may not be relevant when considering views of survivors who do not attend follow-up care for whatever reason.

We aimed to describe 1) preferences for different organizational aspects and models of follow-up care among Swiss childhood cancer survivors

(including both current attenders and non-attenders to follow-up care), and 2) characteristics of survivors associated with preferences for different models of care.

METHODS

Sample and procedure

The Swiss Childhood Cancer Registry (SCCR) is a population-based registry including all Swiss residents diagnosed before age 21 years with leukaemia, lymphoma, central nervous system (CNS) tumour, malignant solid tumour or Langerhans cell histiocytosis (Michel *et al.*, 2007, Michel *et al.*, 2008). The Swiss Childhood Cancer Survivor Study (SCCSS) is a nationwide, long-term follow-up study of all patients registered in the SCCR who were diagnosed between 1976-2005 and survived for ≥5 years (Kuehni *et al.*, 2012a).

For the baseline survey, between 2007-2009, all survivors aged older than 16 years at study received an information letter about the study from their treating institution. They were asked whether or not they wished to participate, their address, or if they required the baseline questionnaire in another language (German, French, and Italian). Two weeks later, all survivors received a paper-based questionnaire (baseline) with a prepaid return envelope. Non-responders received another questionnaire after 2 months and then were contacted by phone if they did not respond.

After approximately 3 years all participants who had completed the baseline questionnaire, were aged ≥18 years, and diagnosed with cancer at age ≤16 years between 1990-2005, received a follow-up questionnaire. Non-responders to this questionnaire were sent a reminder letter with a questionnaire and prepaid return envelope two months later. Because there were few Italian speaking participants, the second questionnaire was provided only in German and French. For the current study survivors whose parents completed the baseline questionnaire were excluded.

Ethics approval was provided through the general cancer registry of the SCCR (The Swiss Federal Commission of Experts for Professional Secrecy in Medical Research) and a non obstat statement (the ethical committee did not object to the running of the study) was obtained from the ethics committee of the canton of Bern. Participants gave informed consent for the study by returning the completed questionnaire.

The questionnaires

The baseline questionnaire was based on those used in the US and UK childhood cancer survivor studies (Robison *et al.*, 2002, Hawkins *et al.*, 2008), and covered the following topics: quality of life, somatic health, current medication, health service utilization, psychological distress, health behaviour and socio-economic information. The focus of the follow-up questionnaire was follow-up care and psychological outcomes.

Measurements

Baseline questionnaire

We assessed *sex, migration background* and *self-reported late effects*. We coded participants as having a migration background if they were not Swiss citizens, were not born in Switzerland, or at least one parent was not a Swiss citizen. We asked if survivors experience late effects from cancer or treatment (yes/no).

Follow-up questionnaire

Outcome measures:

Follow-up attendance: We asked survivors if they still attended follow-up care (a) “I regularly attend follow-up”, b) “I irregularly attend follow-up”, c) “Follow-up is completed but I visit my treating doctor when I have questions”, d) “Follow-up is completed and I never visit my former treating doctor”. We coded (a) and (b) as attenders [1], and (c) and (d) as non-attenders [0].

Reasons for follow-up (Michel et al., 2009): Survivors rated the importance of different

reasons for attending follow-up (0="not at all important" to 3="very important"). Factor analysis revealed two scales: supportive care (get information about late effects, talk to staff who understand what I've been through, get advice about how to keep healthy, receive psychological support, get advice about everyday things) and clinical care (check the cancer has not come back, get reassurance about health, help clinic staff learn more about late effects, get the best medical care). Cronbach's alpha in our sample indicated a good internal consistency for both scales: supportive care: α=0.80; clinical care α=0.69.

What is important during appointments: Survivors rated the importance of 10 organisational aspects of follow-up appointments (0="not at all important" to 3="very important"): Competent staff, being taken seriously, relationship quality between doctor and patient, insurance reimbursement, doctor continuity across appointments, no long waiting times, regular appointments, short and efficient consultation, nurse continuity across appointments, meeting other survivors.

What should be included in follow-up: We asked about the importance of four clinical aspects (check that cancer has not come back, screen for late effects, provide information on potential late effects, other medical follow-up) and eight general aspects of follow-up (risk of diseases for my children, psychological counselling, availability of alternative medicine, information/counselling about sexuality, information about education / job, exchange with other survivors, support in spiritual aspects of life, other offers). Each aspect was rated on a 4 point scale (0="not at all important" to 3="very important").

Who should be involved in follow-up: Survivors rated how personally important it is that different medical and other specialists are involved in follow-up (0="not at all important" to 3="very important"): paediatric oncologist, general practitioner (GP), medical oncologist, fertility counselling, gynaecologist, endocrinologist, psychologist/psychiatrist, specialist nurse, radiotherapies, nutritional counselling, physiotherapist, geneticist, insurance counselling, social worker, career counselling, other specialist)

Where should follow-up be provided: We asked survivors' agreement (0="don't agree at all" to 3="completely agree") about the place where they would like to attend follow-up: a) at the paediatric hospital, where they were treated, b) a hospital for adults, c) a central, specialised follow-up clinic, d) their GP.

Preferences for models of follow-up care: We provided a short description of five different models of follow-up care: a) telephone/questionnaire based follow-up, b) GP follow-up, c) follow-up by paediatric oncologist who originally treated the patient, d) medical oncologist follow-up, e) hospital-based follow-up by a multidisciplinary team (MDT). For each model we asked survivors if this kind of follow-up would suit them, if they were afraid that health problems would not be detected, if they would not be satisfied with this kind of follow-up, and if they thought that this kind of follow-up was appropriate for their health (0="don't agree at all" to 3="completely agree"). Two items were reverse coded such that a higher score indicated higher positive agreement for the respective model (0-3). We calculated the mean of the four items to indicate agreement with each model. For model e) we asked 4 additional items, which were analysed separately (I can contact all specialists I need, I can be referred to the right specialist, follow-up is less personal, I don't know who is responsible for me).

Socio-demographic characteristics and psychological distress:

Psychological distress: We used the Brief Symptom Inventory-18 (BSI-18)(Derogatis, 2000) and calculated scores for somatisation, depression, anxiety, and a Global Severity Index (GSI). Survivors rated how much they experienced each symptom during the 7 previous days on a 5-point scale (1="not at all" to 5="extremely"). Scale scores were converted into T-scores (mean=50; standard deviation (SD)=10). We created a case-indicator specifying survivors with high distress (T≥57 on at least 2 scales or the GSI) (Zabora *et al.*, 2001,

Gianinazzi *et al.*, 2013). Cronbach's α in our sample indicated a good internal consistency for all three scales and the GSI(somatization: α=0.78; depression: α=0.90; anxiety: α=0.80; GSI α=0.91). *Educational achievement* was coded as primary (compulsory schooling), secondary (vocational training or high school degree), and tertiary education (college or university degree) (Kuehni *et al.*, 2012b). *Employment* was coded as "employed", "in education" or "not employed". *Partnership* was coded as not having a partner vs. being in a partnership. *Age at study* was coded into ≤25 years and >25 years. The *language* was coded into German and French.

Data available from the SCCR

Age at diagnosis was coded into 0-4 years, 5-9 years, 10+ years. *Time since diagnosis* was coded into 5-9 years, 10-14 years, 15+years. *Diagnoses* were classified according to the International Classification of Childhood Cancer-3rd edition) (Steliarova-Foucher *et al.*, 2005). We recoded diagnoses into four major groups: leukaemia, lymphoma, CNS tumours and other solid tumours. *Treatment* was coded as surgery only, chemotherapy (without radiotherapy, may have had surgery), radiotherapy (may have had surgery and/or chemotherapy) and stem cell transplantation (SCT). *Relapse* and *second malignancy* were coded as yes/no.

Analyses

All analyses were performed using Stata 13.0 (StataCorp, College Station, TX). Numbers for each outcome vary because not all participants answered all questions. We used descriptive statistics and chi^2-test to compare participants and non-participants in the study. To analyse aim 1 (preferences for different organizational aspects and models of follow-up care) we used means and proportions to describe different preferences for organizational aspects and models of follow-up care. Paired t-tests were used to compare the importance of clinical and supportive reasons, and as *post-hoc* test following Hotelling T-test for the comparison of more than two means. We used t-test and chi^2-test to analyse differences in preferences between attenders and non-attenders to follow-up. To evaluate aim 2 (characteristics of survivors associated with preferences for different models of care), we used univariable and multivariable linear regression analyses using the mean satisfaction with each model of care as outcome. We ran separate regression analyses for each of the five described models of follow-up care. For multivariable regressions, we included all variables, which were significantly associated at $p<0.05$ in the univariable regressions for at least one of the follow-up models.

RESULTS

A total of 754 survivors were eligible for the follow-up questionnaire. We were able to contact 720 of these, and 314 were included in the study (43.6%; Figure 1). Participants' characteristics are described in Table 1. Participants were more likely than non-participants to be female, and to have received radiotherapy, but less likely to have had surgery only.

1) Preferences for the organisation of follow-up care

Of the 314 responders, 150 (47.8%) reported they still attended follow-up (Table 1).

Reasons for follow-up: Clinical reasons (mean=2.33, SD=0.58) were more important than supportive reasons (mean=1.61, SD=0.71; $p<0.001$; Figure 2). Most important reasons for survivors to return were to *Check that cancer has not come back* (mean=2.53, SD=0.80) and seek *reassurance about health* (mean=2.44, SD=0.72); least important were to receive *psychological support* (mean=1.30, SD=1.02) and *get advice about everyday things* (mean=1.21, SD=1.00).

What is important during appointments: Survivors reported that *competent staff* (mean=2.74, SD=0.47) and *being taken seriously* (mean=2.70, SD=0.49) were most important to them during appointments (Figure 3), and significantly more important than the *relationship quality* (mean=2.51, SD=0.64; $p<0.001$). *Nurse continuity across appointments* (mean=1.43, SD=0.92) and *meet other survivors* (mean=0.89, SD=0.83) were least important.

What should be included? When asked about clinical aspects that should be included in follow-up survivors agreed that *checking for cancer recurrence* (mean=2.78, SD=0.53) was most important (Figure 3), more than *screening for late effects* (mean=2.67, SD=0.53; p=0.001) and gaining *information on potential late effects* (mean=2.63, SD=0.55; p<0.001). Knowing about *risks for my children* (mean=2.22, SD=0.83) was rated as most important among general aspects. The possibilities for *interaction with other survivors* (mean=0.95, SD=0.86) and getting *advice on spiritual things* were rated as not important (mean=0.42, SD=0.66).

Who should be involved: Paediatric oncologist (mean=2.26, SD=0.96), general practitioners (mean=2.10, SD=0.99) and medical oncologist (mean=2.07, SD=0.95) were rated as most important to be included in follow-up (Figure 3). Other specialists or counselling options such as nutritional counselling (mean=0.99, SD=0.90), physiotherapist (mean=0.99, SD=0.88), geneticist (mean=0.97, SD=0.96), insurance counselling (mean=0.89, SD=0.92), social worker (mean=0.74, SD=0.83), and career counselling (mean=0.69, SD=0.83) were considered less important.

Where should follow-up be provided: Survivors showed no preference for place of follow-up (Figure 3): children's hospital (mean=1.94, SD=1.11), adult hospital (mean=1.86, SD=0.98) or GP practice (mean=1.86, SD=1.01; no significant difference: for all p>0.05). A central specialised late effects clinic was rated least acceptable (mean=1.25, SD=1.06; compared to the three other clinics: p<0.001).

There was little difference in preferences for follow-up between attenders and non-attenders to follow-up (Online Table 1). Attenders reported slightly higher preference for clinical reasons for follow-up (p=0.014), to get the best medical care (p=0.009), and to talk to staff who understood what they had been through (p=0.008). They also valued regular appointments (p<0.001) and information about education or work (p=0.001) higher than non-attenders. Attenders rated presence of endocrinologists (p=0.045) and other specialists (p=0.048) as more important than non-attenders.

Preferred model of follow-up care: Survivors rated paediatric oncologist follow-up (mean=2.24, SD=0.72) and medical oncologist follow-up highest (mean=2.17, SD=0.69; p=0.087). Both these models were rated significantly higher than the other three models (all p<0.001, apart from medical oncologist compared to follow-up by multidisciplinary team [MDT]: p=0.031): MDT follow-up (mean=2.07, SD=0.73), GP follow-up (mean=1.90, SD=0.84), or follow-up by telephone/questionnaire (mean=1.06, SD=0.83). Regarding MDT follow-up, survivors liked being able to contact all specialists they needed (mean=2.27, SD=0.81), and could be referred to the right specialist (mean=2.28, SD=0.77). They did not agree that MDT follow-up might be less personal (mean=1.50, SD=1.04) or might mean they did not know who was responsible for their care (mean=1.13, SD=0.96).

2) Characteristics associated with preferences for different models of follow-up care

In univariable linear regression analyses we determined characteristics of survivors with different preferences for follow-up models (Online Table 2). Attenders rated follow-up by medical oncologist higher, and GP or phone-follow-up lower than non-attenders (Figure 4). Higher ratings of importance of clinical and supportive reasons were associated with all models: higher endorsement of importance of both clinical and supportive reasons were associated with lower rating of telephone/questionnaire and GP follow-up, and higher rating of the other models. Self-reported late effects were associated with lower rating of GP follow-up and higher rating of MDT follow-up. Survivors who received chemotherapy rated GP and paediatric oncologist follow-up highest and survivors undergoing other treatments rated them lower. Psychological distress was only associated with higher rating of importance of?MDT follow-up. Regarding socio-demographic characteristics, survivors older at study and those with higher education rated the paediatric oncologist follow-up lower, and French speaking survivors rated GP follow-up higher. Results of the multivariable linear regression remained similarly in the direction of

the association. However, fewer characteristics remained statistically significant (Table 2).

DISCUSSION

In our study, approximately half of responding survivors continued to attend follow-up. We found that clinical reasons for follow-up such as checking that cancer has not come back or being reassured about their health, were rated higher than supportive reasons. Survivors also expected competent staff at their follow-up, including paediatric or medical oncologists as well as general practitioners. Despite the age of these survivors (≥18 years) they valued going to the children's hospital for follow-up, but adult hospital or GP practice were rated similarly highly. Follow-up by paediatric or medical oncologist were the preferred follow-up models, particularly by those who rated clinical reasons for follow-up as very important.

The high endorsement of medical aspects of follow-up was similar to previous studies (Eiser *et al.*, 1996, Michel *et al.*, 2009, Zebrack *et al.*, 2004, Earle *et al.*, 2005). In a UK study using the same questions, we also found significantly higher importance given to clinical reasons than supportive reasons (Michel *et al.*, 2009). We also found that survivors wanted to discuss clinical topics such as their current health, late effects or medication, rather than general topics such as insurance or work-related issues. Our results also support findings of a US study showing that survivors wanted to be taken seriously by their doctors (Zebrack *et al.*, 2004).

In contrast to UK studies, where GP follow-up was rated comparable with telephone/questionnaire follow-up (Michel *et al.*, 2009, Eiser *et al.*, 1996), Swiss survivors rated GP follow-up highly, though not as much as paediatric or medical oncologist follow-up. The high preference for GP follow-up was also found in a qualitative study in the USA (Zebrack *et al.*, 2004); however, survivors ranked follow-up by a "primary care physician knowledgeable and experienced in working with survivors" (p.849) highest. As GPs do not usually care for many childhood cancer survivors most will lack the required experience. A close collaboration between GP and a specialised late effects clinic might be a solution to this problem (Oeffinger, 2003, Singer *et al.*, 2013). A Dutch study showed the potential of further education about late effects and follow-up care for GPs and that GPs were interested in such a programme (Blaauwbroek *et al.*, 2007).

Swiss survivors rated paediatric oncologist follow-up highest. This is in contrast to a US study, where survivors rated a programme staffed with a paediatric oncologist and nurse practitioner lower than primary care physician follow-up (Zebrack *et al.*, 2004). The high preference for the paediatric oncologist model in Switzerland might be due to the fact that survivors get high quality follow-up provided by their paediatric oncologist for at least 10 years after diagnosis. Therefore, the model describes a model with which they are familiar. Additionally, in Switzerland we have 9 specialised centres for paediatric oncology across the country, so that this model provides appropriate geographical access for most survivors.

Both attenders and non-attenders to follow-up reported similar preferences for the organisation of follow-up. However, attenders valued clinical reasons slightly higher than non-attenders. This may be one of the reasons why survivors continue to attend follow-up while those who consider clinical reasons to be less important do not. However, this needs to be addressed in future work as differences are small.

Expert opinions have often favoured centralised follow-up care by specialists (Essig *et al.*, 2012). Our results suggest that Swiss survivors are not favouring this model; a central specialised late effects clinic was rated lowest among the provided places. Although, given the size of Switzerland, distances to a central clinic would be relatively short for most survivors, this suggests that there is a preference for follow-up to be close to home. Organised transition from paediatric to adult oncology clinic seems a logical way forward and should contribute to optimal follow-up care.

A major strength of this study is the involvement of a population-based sample including both those who attend and those who do not attend follow-up care. In addition, we had access to established information on diagnosis, treatment and relapse from the Swiss Childhood Cancer Registry. We also assessed a wide range of different characteristics of follow-up care so that a detailed picture of survivors' needs could be drawn.

A limitation is that we could not include an objective measure of risk for late effects, apart from general indicators associated with diagnosis, treatment, relapse and second tumour. Depending on this risk, different follow-up models might be clinically preferable (Wallace *et al.*, 2001). For example, survivors with a high risk for late effects might require long-term specialist care while regular GP visits might be sufficient for low-risk survivors. It is not known how far survivors agree or not with these medical views. Another limitation is the low response rate, which might indicate that a large number of survivors are not interested in the topic of follow-up care or not aware of the implications of cancer for their future health.

Follow-up care remains an important aspect of long-term survival after childhood cancer, and will continue to grow in importance as survivors age. It is crucial that long-term follow-up not only respects medical guidelines but is organised according to survivors' needs and preferences. Our study showed that survivors value clinic-based follow-up care by specialists, but also emphasises the necessity to provide care in convenient locations. This needs to be taken into account when considering provision of well-organised long-term follow-up care for adult survivors of childhood cancer.

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Conflict of Interest statement
No conflict of interest for any of the authors.

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Table 1: Sample description: Survivors who responded to the baseline questionnaire only compared to survivors who responded to both questionnaires

	Non-participants		Participants		
	N	%	N	%	p*
Total	440	100.0	314	100.0	
Socio-demographic characteristics					
Sex					<0.001
Male	252	57.3	138	43.9	
Female	188	42.7	176	56.1	
Age at study					0.283
≤25 years	292	66.4	220	70.1	
>25 years	148	33.6	94	29.9	
Migration background					0.204
No migration background	348	79.1	260	82.8	
Migration background	92	20.9	54	17.2	
Language					0.785
German	324	73.6	234	74.5	
French / Italian	116	26.4	80	25.5	
Partnership					
No partner			186	59.2	
Has partner			128	40.8	
Education					
Vocational training			177	56.4	
Compulsory schooling			69	22.0	
Upper secondary/ university education			68	21.7	
Employment					
Not employed			20	6.4	
Employed			190	60.5	
In education			104	33.1	
Clinical characteristics					
Diagnosis					0.526
Leukaemia	136	30.9	113	36.0	
Lymphoma	89	20.2	59	18.8	
CNS tumour	71	16.1	36	11.5	
Neuroblastoma	15	3.4	8	2.5	
Retinoblastoma	10	2.3	5	1.6	
Renal tumour	22	5.0	21	6.7	
Hepatic tumour	3	0.7	1	0.3	
Bone tumour	24	5.5	22	7.0	
STS	21	4.8	20	6.4	
Germ cell tumour	20	4.5	9	2.9	
Carcinoma	6	1.4	7	2.2	
Other neoplasm	1	0.2	1	0.3	
LCH	22	5.0	12	3.8	
Treatment					0.030
Chemotherapy	191	43.4	137	43.6	
Surgery only	77	17.5	32	10.2	
Radiotherapy	135	30.7	114	36.3	
SCT	37	8.4	31	9.9	
Age at diagnosis					0.225
0-4 years	107	24.3	86	27.4	
5-9 years	134	30.5	78	24.8	
10+ years	199	45.2	150	47.8	

Table 1 continued

	Non-participants		Participants		
	N	%	N	%	p*
Time since diagnosis					0.102
16+ years	253	57.5	177	56.4	
11-15 years	144	32.7	91	29.0	
5-10 years	43	9.8	46	14.6	
Relapse					0.309
No relapse	397	90.2	276	87.9	
Relapse	43	9.8	38	12.1	
Second malignancy					0.580
None	418	95.0	301	95.9	
Has second malignancy	22	5.0	13	4.1	
Late effects					0.077
No late effects reported	276	62.7	184	58.6	
Late effects reported	145	33.0	127	40.4	
Psychological distress					
No distress			232	73.9	
Psychological distress			79	25.2	
Follow-up attendance					
Regularly attends follow-up			128	40.8	
Irregularly attends follow-up			22	7.0	
Follow-up completed, visits treating doctor for questions			41	13.1	
Follow-up completed, never visit former treating doctor			123	39.2	
	mean	SD	mean	SD	p#
Age at study	24.3	4.2	24.1	4.4	0.584
Age at diagnosis	8.7	4.5	8.9	4.6	0.622
Time since diagnosis	15.5	3.7	15.2	4.0	0.381

*p from chi2 tests, #p from two sample t-tests, STS Soft tissue sarcomas, LCH Langerhans cell histiocytosis, SCT Stem cell transplantation

Table 2: Multivariable linear regression analyses describing characteristics associated with different follow-up model preferences

Follow-up by	Telephone / Questionnaire				General Practitioner				Paediatric Oncologist				Medical Oncologist				Multidisciplinary team			
	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p
Intercept	1.91	1.49	2.32		2.54	2.14	2.95		1.91	1.56	2.27		1.55	1.20	1.89		1.52	1.15	1.88	
Age at study																				
<=25 years																				
>25 years	0.07	-0.17	0.32	0.551	-0.05	-0.28	0.19	0.706	-0.18	-0.39	0.03	0.088	-0.17	-0.37	0.04	0.110	0.01	-0.20	0.23	0.907
Language																				
German																				
French/Italian	0.16	-0.07	0.38	0.171	0.33	0.11	0.55	0.004	-0.12	-0.31	0.08	0.234	-0.04	-0.24	0.15	0.643	-0.08	-0.28	0.12	0.448
Education																				
Vocational training																				
Compulsory schooling	-0.05	-0.28	0.19	0.706	-0.11	-0.34	0.13	0.376	0.24	0.03	0.45	0.024	-0.02	-0.22	0.18	0.836	0.03	-0.19	0.24	0.813
Upper secondary/ university	0.11	-0.15	0.37	0.391	-0.03	-0.28	0.23	0.820	0.02	-0.21	0.24	0.892	0.10	-0.12	0.32	0.351	0.10	-0.13	0.33	0.401
Treatment																				
Chemotherapy																				
Surgery only	-0.02	-0.34	0.31	0.924	-0.29	-0.61	0.03	0.074	-0.43	-0.71	-0.15	0.003	0.00	-0.28	0.27	0.975	-0.15	-0.44	0.14	0.308
Radiotherapy	-0.03	-0.25	0.19	0.775	-0.14	-0.36	0.07	0.188	-0.18	-0.36	0.01	0.066	0.03	-0.16	0.21	0.785	-0.01	-0.21	0.18	0.890
SCT	-0.10	-0.44	0.24	0.551	-0.10	-0.43	0.24	0.563	-0.29	-0.59	0.00	0.049	-0.16	-0.45	0.13	0.271	-0.12	-0.42	0.19	0.451
Follow-up																				
Follow-up attender																				
Not attending follow-up	-0.19	-0.39	0.00	0.055	-0.21	-0.41	-0.02	0.033	0.10	-0.07	0.27	0.259	0.18	0.01	0.35	0.034	0.00	-0.18	0.17	0.984
Clinical Reasons for follow-up (continuous 0-3)																				
Intercept																				
per 1 point increase	-0.34	-0.54	-0.14	0.001	-0.04	-0.24	0.16	0.691	0.11	-0.06	0.29	0.197	0.31	0.14	0.48	0.000	0.12	-0.06	0.29	0.198
Supportive Reasons for follow-up (continuous 0-3)																				
Intercept																				
per 1 point increase	0.03	-0.15	0.20	0.750	-0.22	-0.39	-0.05	0.011	0.12	-0.03	0.27	0.111	-0.10	-0.24	0.05	0.195	0.12	-0.04	0.27	0.130
Psychological distress (BSI case)																				
No distress																				
Significant distress	-0.14	-0.36	0.07	0.197	-0.07	-0.28	0.15	0.543	0.05	-0.14	0.24	0.628	0.10	-0.08	0.29	0.270	0.16	-0.03	0.36	0.102
Late effects																				
None																				
Late effects reported	-0.01	-0.21	0.19	0.923	-0.09	-0.28	0.11	0.374	-0.07	-0.25	0.10	0.394	-0.03	-0.20	0.14	0.710	0.20	0.03	0.38	0.025

Coeff: Coefficient, CI: Confidence Interval, SCT: Stem cell transplantation, BSI case: survivor with high distress in the Brief Symptom Inventory (T≥57 on at least 2 scales or the Global severity index)

FIGURE LEGENDS

Figure 1: Participant and non-participant of the study

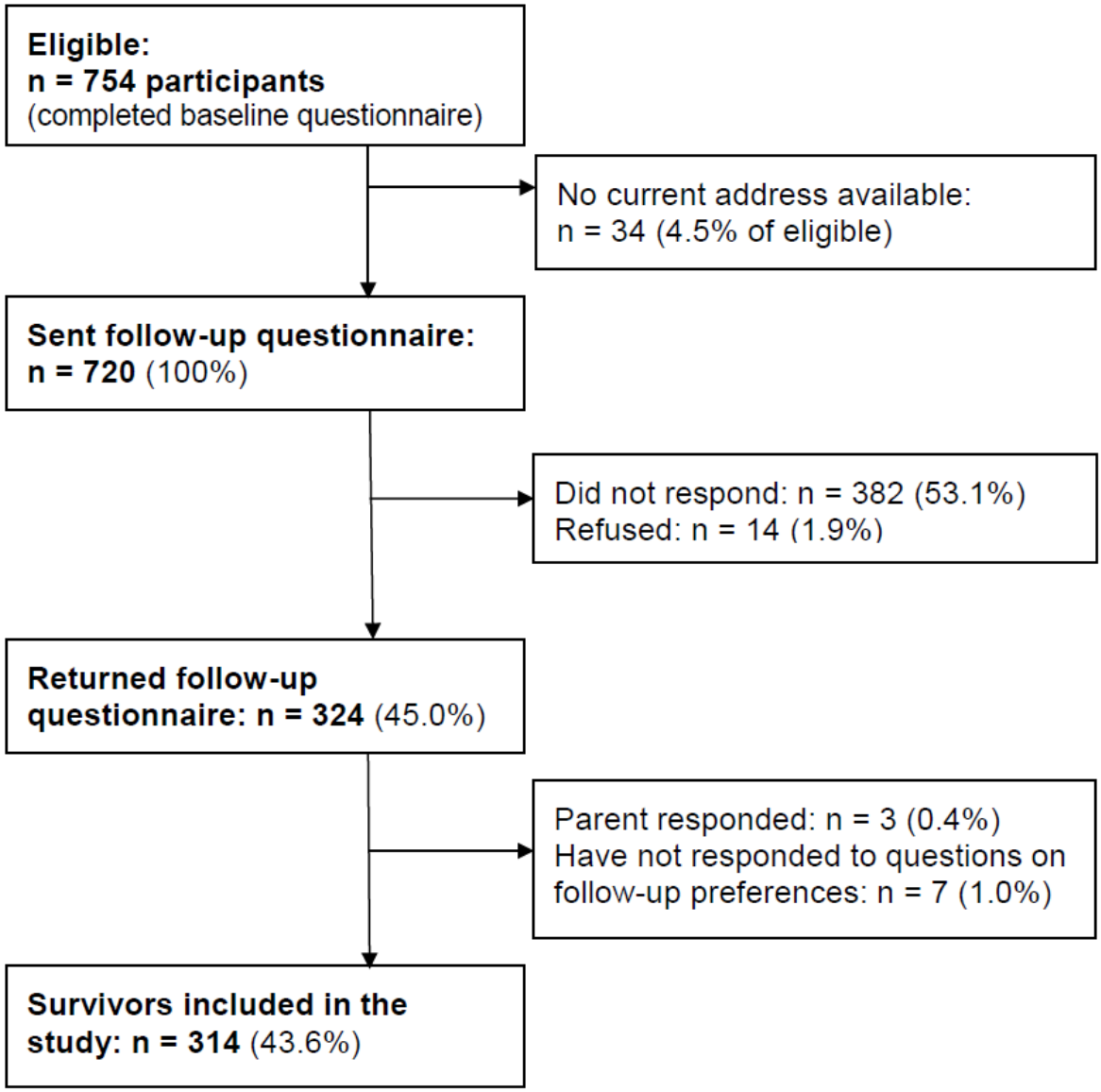


Figure 2: Reasons for follow-up care (0 not important to 3 very important; mean and 95% confidence interval)

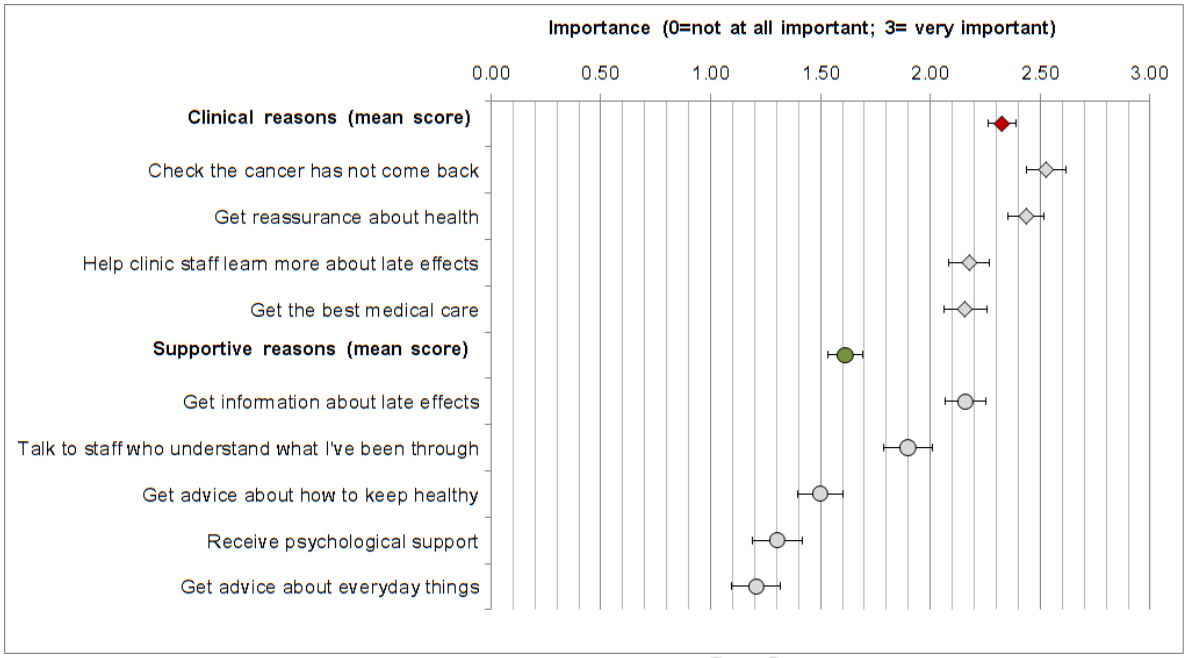


Figure 3: Importance of different aspects of follow-up (0 not important to 3 very important; mean and 95% confidence interval)

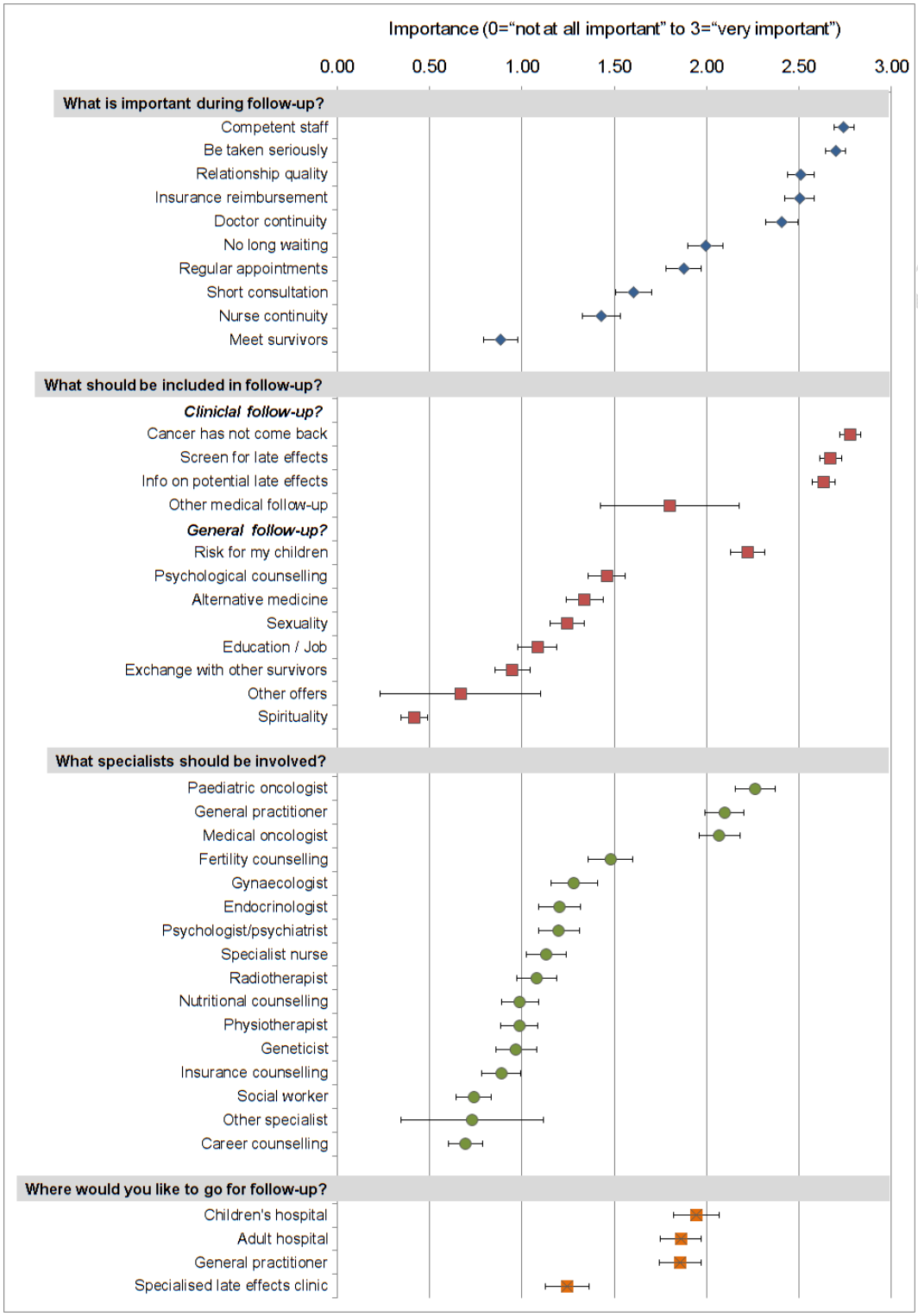
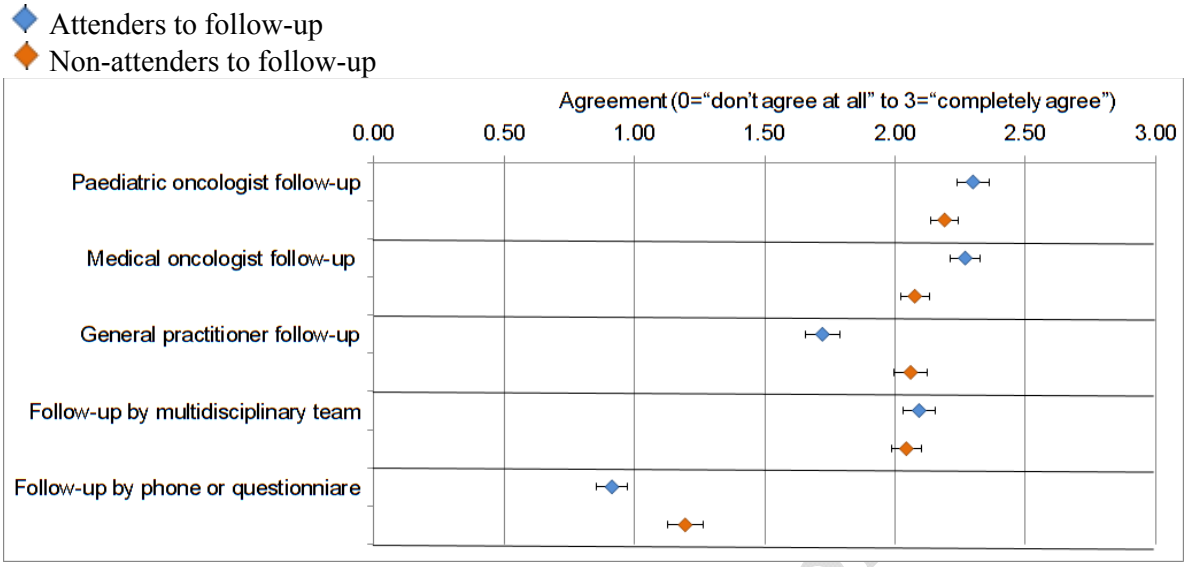


Figure 4: Preferences for different models of follow-up care among attenders and non-attenders to follow-up (mean agreement with 4 items)

Non-attenders: reported not attending follow-up regularly or irregularly; attenders: reported attending follow-up regularly or irregularly



Online Table 1: Differences in preferences for the organisation of follow-up between attenders and non-attenders to follow-up

	Non-attenders		Attenders		
	Mean	95%CI	Mean	95%CI	p*
Reasons for follow-up care					
Clinical reasons (mean score)	2.25	(2.15-2.34)	2.41	(2.32-2.49)	0.014
Check the cancer has not come back	2.48	(2.35-2.62)	2.57	(2.45-2.69)	0.346
Get reassurance about health	2.36	(2.24-2.48)	2.51	(2.41-2.62)	0.065
Help clinic staff learn more about late effects of Cancer/treatment	2.10	(1.96-2.24)	2.25	(2.13-2.38)	0.114
Get the best medical care	2.03	(1.88-2.18)	2.29	(2.17-2.41)	0.009
Supportive reasons (mean score)	1.54	(1.43-1.65)	1.69	(1.57-1.81)	0.065
Get information about late effects of cancer	2.17	(2.03-2.30)	2.15	(2.02-2.29)	0.888
Talk to staff who understand what I've been through	1.75	(1.59-1.91)	2.05	(1.90-2.21)	0.008
Get advice about how to keep healthy	1.44	(1.29-1.58)	1.56	(1.41-1.71)	0.228
Receive psychological support	1.23	(1.07-1.39)	1.38	(1.21-1.54)	0.218
Get advice about everyday things like insurance	1.12	(0.96-1.27)	1.30	(1.14-1.47)	0.105
What is important during follow-up?					
Competent staff	2.74	(2.67-2.82)	2.74	(2.66-2.82)	0.945
Be taken seriously	2.70	(2.62-2.77)	2.70	(2.62-2.78)	0.938
Relationship quality	2.49	(2.39-2.59)	2.53	(2.43-2.63)	0.619
Insurance reimbursement	2.48	(2.37-2.58)	2.53	(2.41-2.65)	0.473
Doctor continuity	2.34	(2.22-2.45)	2.48	(2.36-2.61)	0.093
No long waiting	2.08	(1.95-2.21)	1.90	(1.76-2.04)	0.063
Regular appointments	1.71	(1.58-1.84)	2.05	(1.92-2.18)	<0.001
Short consultation	1.65	(1.51-1.79)	1.56	(1.42-1.70)	0.400
Nurse continuity	1.39	(1.24-1.53)	1.48	(1.33-1.63)	0.383
Meet survivors	0.90	(0.77-1.04)	0.87	(0.74-1.00)	0.759
What should be included in follow-up?					
Medical follow-up					
Cancer has not come back	2.73	(2.64-2.82)	2.83	(2.75-2.90)	0.110
Screen for late effects	2.64	(2.55-2.73)	2.70	(2.62-2.78)	0.324
Info on potential late effects	2.62	(2.53-2.70)	2.65	(2.57-2.74)	0.548
Other medical FU	1.78	(1.26-2.30)	1.83	(1.21-2.45)	0.902
General follow-up					
Risk for my children	2.23	(2.11-2.36)	2.21	(2.08-2.35)	0.858
Psychological counselling	1.42	(1.29-1.56)	1.50	(1.34-1.65)	0.476
Alternative medicine	1.26	(1.12-1.40)	1.43	(1.28-1.58)	0.093
Sexuality	1.22	(1.09-1.35)	1.28	(1.15-1.40)	0.555
Education / Job	0.91	(0.77-1.05)	1.28	(1.12-1.43)	0.001
Exchange with other survivors	0.91	(0.77-1.06)	0.99	(0.86-1.12)	0.465
Other offers	0.76	(0.10-1.43)	0.54	(-0.14-1.22)	0.621
Spirituality	0.35	(0.25-0.45)	0.49	(0.38-0.60)	0.076

Online Table 1 continued

	Non-attenders		Attenders		
	Mean	95%CI	Mean	95%CI	p*
What medical and non-medical specialists should be involved in follow-up?					
Paediatric Oncologist	2.33	(2.18-2.47)	2.19	(2.02-2.36)	0.221
General practitioner	2.13	(1.98-2.27)	2.07	(1.91-2.23)	0.596
Medical Oncologist	1.98	(1.82-2.14)	2.17	(2.01-2.33)	0.101
Fertility counselling	1.51	(1.34-1.68)	1.45	(1.28-1.62)	0.647
Gynaecologist	1.20	(1.03-1.37)	1.38	(1.19-1.56)	0.157
Psychologist/Psychiatrist	1.19	(1.04-1.35)	1.20	(1.04-1.37)	0.935
Radiotherapies	1.15	(1.00-1.30)	1.00	(0.84-1.16)	0.162
Specialist nurse	1.12	(0.97-1.28)	1.14	(0.99-1.30)	0.867
Endocrinologist	1.09	(0.94-1.24)	1.32	(1.15-1.50)	0.045
Geneticist	1.03	(0.88-1.19)	0.90	(0.74-1.06)	0.237
Physiotherapist	0.98	(0.84-1.12)	0.99	(0.85-1.14)	0.907
Nutritional counselling	0.96	(0.81-1.10)	1.03	(0.88-1.18)	0.484
Insurance counselling	0.90	(0.75-1.04)	0.88	(0.73-1.03)	0.871
Social worker	0.70	(0.58-0.82)	0.78	(0.64-0.93)	0.386
Career counselling	0.66	(0.53-0.78)	0.74	(0.59-0.88)	0.397
Other specialist	0.33	(-0.05-0.71)	1.11	(0.43-1.78)	0.048
Where would you like to go for follow-up?					
Follow-up at general practitioner	1.94	(1.78-2.10)	1.76	(1.60-1.92)	0.109
Follow-up at children's hospital	1.93	(1.76-2.10)	1.96	(1.77-2.14)	0.831
Follow-up at adult hospital	1.92	(1.78-2.07)	1.79	(1.62-1.97)	0.249
Follow-up at specialised late effect clinic	1.29	(1.12-1.46)	1.19	(1.02-1.36)	0.428

95%CI: 95% confidence interval
* p from t-tests for comparison between groups

Online Table 2: Univariable linear regression analyses describing characteristics associated with different follow-up model preferences

Follow-up by	Telephone / Questionnaire				General Practitioner				Paediatric Oncologist				Medical Oncologist				Multidisciplinary team			
	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p
Total	1.06	0.97	1.15		1.90	1.81	1.99		2.24	2.16	2.32		2.17	2.09	2.25		2.07	1.99	2.15	
Sex				0.527				0.709				0.792				0.086				0.095
Male	1.09	0.96	1.23		1.88	1.74	2.02		2.23	2.11	2.35		2.09	1.98	2.21		1.99	1.87	2.11	
Female	-0.06	-0.25	0.13		0.04	-0.15	0.22		0.02	-0.14	0.18		0.14	-0.02	0.29		0.14	-0.02	0.30	
Age at study				0.306				0.684				0.001				0.119				0.297
<=25 years	1.03	0.92	1.14		1.91	1.80	2.02		2.33	2.24	2.43		2.21	2.12	2.30		2.04	1.94	2.14	
>25 years	0.10	-0.10	0.31		-0.04	-0.25	0.16		-0.30	-0.47	-0.13		-0.13	-0.30	0.03		0.09	-0.08	0.27	
Parent or child migration background				0.425				0.816				0.387				0.997				0.599
no migration background	1.04	0.94	1.15		1.90	1.80	2.01		2.26	2.17	2.35		2.17	2.08	2.26		2.06	1.97	2.15	
migration background	0.10	-0.15	0.34		-0.03	-0.28	0.22		-0.09	-0.31	0.12		0.00	-0.21	0.21		0.06	-0.16	0.27	
Language				0.231				0.003				0.723				0.773				0.972
German	1.03	0.92	1.14		1.82	1.71	1.92		2.25	2.16	2.34		2.18	2.09	2.27		2.07	1.97	2.16	
French	0.13	-0.08	0.34		0.32	0.11	0.53		-0.03	-0.22	0.15		-0.03	-0.20	0.15		0.00	-0.19	0.19	
Partner				0.268	0.00	0.00	0.00	0.188				0.351				0.497				0.317
No	1.10	0.98	1.22		1.95	1.83	2.07		2.21	2.11	2.32		2.15	2.05	2.25		2.03	1.93	2.14	
Yes	-0.11	-0.29	0.08		-0.13	-0.32	0.06		0.08	-0.09	0.24		0.05	-0.10	0.21		0.08	-0.08	0.25	
Education				0.243				0.284				0.001				0.948				0.334
Vocational training	1.05	0.92	1.17		1.95	1.83	2.07		2.20	2.10	2.31		2.17	2.07	2.28		2.02	1.91	2.13	
Compulsory schooling	-0.08	-0.31	0.15		-0.19	-0.42	0.04		0.31	0.11	0.51		0.01	-0.19	0.21		0.09	-0.12	0.29	
Upper secondary/ university	0.15	-0.08	0.38		-0.05	-0.28	0.19		-0.13	-0.33	0.07		-0.03	-0.22	0.17		0.15	-0.06	0.36	
Employment				0.599				0.117				0.845				0.112				0.152
not employed	1.23	0.86	1.59		1.59	1.22	1.95		2.21	1.88	2.54		1.91	1.60	2.22		1.76	1.43	2.09	
employed	-0.19	-0.58	0.19		0.37	-0.01	0.76		0.02	-0.32	0.36		0.32	-0.01	0.64		0.31	-0.04	0.65	
in education	-0.15	-0.54	0.25		0.26	-0.14	0.66		0.07	-0.29	0.42		0.21	-0.13	0.55		0.35	0.00	0.71	
Clinical characteristics																				
Diagnosis				0.434				0.247				0.068				0.241				0.827
Leukaemias	1.01	0.85	1.16		1.94	1.78	2.09		2.30	2.17	2.43		2.12	1.99	2.25		2.05	1.91	2.19	
Lymphomas	-0.04	-0.30	0.23		0.06	-0.20	0.32		-0.03	-0.25	0.20		0.10	-0.12	0.32		0.02	-0.21	0.26	
CNS tumours	0.07	-0.24	0.38		-0.28	-0.60	0.03		-0.36	-0.63	-0.09		-0.11	-0.38	0.16		-0.06	-0.35	0.22	
Other	0.15	-0.07	0.38		-0.05	-0.27	0.18		-0.04	-0.23	0.16		0.13	-0.05	0.32		0.06	-0.13	0.26	
Treatment				0.412				0.034				0.006				0.958				0.699
Chemotherapy	1.11	0.97	1.25		2.04	1.90	2.18		2.40	2.28	2.52		2.18	2.06	2.30		2.08	1.96	2.20	
Surgery only	0.05	-0.27	0.37		-0.42	-0.74	-0.10		-0.40	-0.68	-0.13		-0.03	-0.30	0.24		-0.12	-0.41	0.17	
Radiotherapy	-0.08	-0.29	0.12		-0.22	-0.43	-0.01		-0.24	-0.42	-0.06		0.01	-0.17	0.18		0.03	-0.16	0.21	
SCT	-0.24	-0.57	0.08		-0.19	-0.52	0.13		-0.25	-0.53	0.03		-0.06	-0.34	0.21		-0.10	-0.38	0.19	

Follow-up by	Telephone / Questionnaire				General Practitioner				Paediatric Oncologist				Medical Oncologist				Multidisciplinary team			
	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p	Coeff	95% CI		p
Age at diagnosis				0.665				0.819				0.132				0.174				0.731
0-4 years	1.06	0.89	1.24		1.93	1.76	2.11		2.37	2.21	2.52		2.10	1.95	2.26		2.02	1.86	2.17	
5-9 years	0.07	-0.19	0.32		-0.01	-0.27	0.24		-0.22	-0.44	0.00		-0.01	-0.23	0.20		0.05	-0.17	0.28	
10+ years	-0.04	-0.26	0.18		-0.07	-0.29	0.16		-0.14	-0.33	0.05		0.14	-0.05	0.33		0.08	-0.12	0.28	
Time since diagnosis				0.446				0.970				0.068				0.062				0.301
16+ years	1.11	0.99	1.24		1.91	1.78	2.03		2.16	2.05	2.27		2.10	2.00	2.21		2.02	1.91	2.13	
11-15 years	-0.13	-0.34	0.08		-0.03	-0.24	0.19		0.19	0.01	0.38		0.09	-0.08	0.27		0.15	-0.04	0.33	
5-10 years	-0.10	-0.37	0.17		-0.01	-0.29	0.26		0.19	-0.05	0.42		0.27	0.04	0.49		0.02	-0.22	0.26	
Relapse				0.602				0.783				0.633				0.291				0.891
No relapse	1.05	0.95	1.15		1.89	1.80	1.99		2.25	2.16	2.34		2.19	2.10	2.27		2.07	1.98	2.16	
Relapse	0.07	-0.21	0.36		0.04	-0.25	0.33		-0.06	-0.31	0.19		-0.13	-0.36	0.11		-0.02	-0.27	0.23	
Second tumour				0.852				0.882				0.254				0.299				0.959
None	1.06	0.97	1.16		1.90	1.81	2.00		2.25	2.17	2.34		2.16	2.08	2.24		2.07	1.98	2.15	
Second tumour	-0.04	-0.51	0.42		-0.04	-0.50	0.43		-0.23	-0.64	0.17		0.20	-0.18	0.59		-0.01	-0.42	0.40	
Follow-up				0.003				0.000				0.183				0.014				0.557
Follow-up attender	1.20	1.07	1.32		2.06	1.93	2.19		2.19	2.08	2.30		2.08	1.97	2.18		2.04	1.93	2.16	
Not attending follow-up	-0.28	-.46	0.10		-0.34	-.52	-0.16		0.11	-0.05	0.27		0.19	0.04	0.35		0.05	-0.12	0.21	
Clinical Reasons for follow-up (linear 0-3)				0.000	0.00			0.023				0.001				0.000				0.019
Intercept	1.90	1.52	2.28		2.33	1.94	2.71		1.70	1.36	2.03		1.55	1.23	1.86		1.67	1.33	2.01	
per 1 point increase	-0.36	-0.52	-0.20		-0.19	-0.35	-0.03		0.24	0.10	0.37		0.27	0.14	0.40		0.17	0.03	0.31	
Supportive Reasons for follow-up (linear 0-3)				0.017				0.001				0.002				0.199				0.002
Intercept	1.33	1.09	1.56		2.24	2.02	2.47		1.95	1.75	2.15		2.05	1.86	2.25		1.78	1.58	1.98	
per 1 point increase	-0.16	-0.29	-0.03		-0.22	-0.35	-0.09		0.18	0.07	0.30		0.07	-0.04	0.18		0.18	0.07	0.29	
Psychological distress (BSI case)				0.155				0.202				0.706				0.690				0.028
No distress	1.11	1.00	1.21		1.93	1.82	2.04		2.23	2.14	2.32		2.16	2.07	2.25		2.02	1.93	2.12	
Significant distress	-0.15	-0.37	0.06		-0.14	-0.35	0.08		0.04	-0.15	0.22		0.04	-0.14	0.21		0.21	0.02	0.40	
Late effects				0.584				0.038				0.214				0.411				0.007
None	1.09	0.97	1.21		1.98	1.86	2.10		2.29	2.19	2.40		2.20	2.10	2.30		1.98	1.87	2.08	
Late effects reported	-0.05	-0.24	0.14		-0.20	-.38	-0.01		-0.10	-0.27	0.06		-0.07	-0.23	0.09		0.23	0.06	0.39	

Coeff: Coefficient, CI: Confidence Interval, CNS: Central nervous system, SCT: Stem cell transplantation, BSI case: survivor with high distress in the Brief Symptom Inventory (T≥57 on at least 2 scales or the Global severity index)